Propranolol for the treatment of haemangiomas in children

Patient Information

Who is the leaflet for? What is its aim?
This leaflet has been developed to provide advice and information to parents and carers administering propranolol to infants in order to reduce the appearance of his/her haemangioma.

What is a haemangioma?
Haemangiomas are soft tissue growths connected to the circulatory system and filled with blood. Their appearance depends on location. If they are on the surface of the skin they look like a ripe strawberry, if they are just under the skin they present as a bluish swelling. Sometimes they grow in internal organs such as the liver or larynx (airway).

How did my child get a haemangioma?
They are formed during pregnancy and most commonly they are not present at birth, but appear during the first few weeks of life. They are often misdiagnosed, initially, as a scratch or bruise, but the diagnosis becomes obvious with further growth. Sometimes they present as a flat red or pink area.

What is propranolol?
Propranolol is a type of medication called a beta blockers that is used to treat high blood pressure in adults. Its use to treat the haemangiomas of children has been used for > 10 years and it has been used to treat children with heart conditions for a long time.

Benefits
These will vary depending upon where on your child’s body their haemangioma is. However, generally speaking, the main benefit your child will experience from taking this medication is to reduce the size of their haemangioma.

Is it safe?
All possible risks will be explained to you in detail prior to your child commencing propranolol therapy.
They include (in order of frequency):

- Low pulse rate (bradycardia)
- Low blood pressure (hypotension)
- Constriction or spasm of the tissue in the lungs (bronchospasm)
- Low blood sugar level (hypoglycaemia)
- Cardiac conduction disorder (an altered pattern in the way the heart works)
- Narrowing of the blood vessels in the limbs (vasoconstriction; which may mean that your child’s hands and feet feel cold)
- Weakness and fatigue
- Sleep disturbance

Alternatives

Please discuss any concerns that you have regarding this topic with the medical team at your child’s next consultation.

What happens next?

Preparation before commencing treatment

Following referral for treatment by your child’s consultant, arrangements will be made for your child to be reviewed by a paediatric cardiologist in clinic 6.

After the decision has been made, in conjunction with yourself, to start a propranolol treatment regime arrangements will be made for your child to be admitted to Ward F3 (a children’s ward) to commence their medication by the paediatric cardiology CNS. The propranolol medication is administered to your child orally in a suspension form (like Calpol).

It is necessary for your child to be admitted to hospital for the five-six hours on the first day of treatment and for a further five-six hours, around a week later, when the dose is doubled. It is important that you remember to bring your supply of propranolol as we will use your medicine during the admissions.

In between these two admissions; and for all subsequent dose increases, you administer the medication yourself at home. Admission to hospital is necessary when commencing propranolol so that your child’s wellbeing can be closely monitored by a nursing and medical team.

Arrangements will be made for your child to be re-admitted to ward F3, 7-10 days later for review and for the propranolol dose to be increased, whilst he/she is once more under observation.

You are, of course, free to come and go as you like. However, we do encourage you to be present with your child throughout their two admissions.
Investigations prior to the commencement of medication will involve recording your child’s weight, blood pressure, a physical examination, a photograph of your child’s haemangioma, blood tests and an echocardiogram (a scan of your child’s heart to assess its structure and function) and a 12 lead ECG (electrocardiogram). These may be conducted either on the day of, or during the week before, admission.

The medication will need to be collected from Lloyds pharmacy (near Clinic 6) before admission to F3.

**How long will my child need this medication for?**

**Treatment regime**

**Week one:** A dose of 1mg per kilogram of your child’s body weight per day divided into three doses (a 6 kilogram child would receive a dose of 2mg three times a day).

**Week two:** The dose will be increased to 2mg per kilogram of your child’s body weight per day divided into three doses. This increase in dose will take place following an assessment to ensure compliance and tolerance of treatment.

**NB.** It is important that you remember to bring your child's propranolol to the all admission to avoid delay in treatment.

**Ongoing:** The propranolol dose will be increased in line with your child’s weight gain at subsequent clinic visits. The duration of treatment will be determined by your child’s referring consultant and will usually be continued until about one year of age, this will depending on child’s response to treatment.

**Follow-up care**

A follow-up telephone appointment with the paediatric cardiology CNS will be arranged for your child in six to eight weeks after commencing treatment.

Long term follow-up will be provided by the referring consultant, (dermatology, plastics, ENT or ophthalmology) to assess your child’s haemangioma’s response to treatment.

You will be asked to sign consent forms for clinical photographs to be taken of your child’s haemangioma, at several stages throughout your child’s treatment, as deemed necessary by your child’s consultant. This is so that an accurate record of your child’s treatment and their response to the propranolol can be made.

**Dosing**

At home you will be giving the propranolol 3 times a day. You should give it first thing in the morning, in the middle of the day and before bed. You do not need to wake your child up to give a dose at night.

**Stop the propranolol if your child develops an episode of bronchiolitis or wheeze.**

Restart the propranolol once they are well they are well in themselves.
Stop the propranolol if your child has an episode of gastroenteritis with diarrhoea and vomiting. Restart the propranolol as normal once they have started eating & drinking again. It is recommended that babies are given the evening dose with their evening milk and also feed during the night time. Paracetamol is safe to be given alongside Propranolol if required.

It is recommended to avoid teething gels containing lignocaine when on Propranolol, speak to your pharmacist about alternative gels.

Stopping treatment

Your child’s propranolol medication will not be stopped on one go. Instead, the dose of propranolol that your child receives will be gradually reduced over two weeks by your consultant halving the dose every week.

Contacts/further information

If you have any concerns relating to your child’s immediate health please contact your general practitioner.

Alternatively, if the matter is a query relating to your child’s diagnosis and is non urgent, please be sure to ask your questions at your next outpatient appointment, or, contact one of the following:

- **Clinical nurse specialist for paediatric cardiology,**
  Department of paediatric cardiology
  Box 267, Addenbrooke’s Hospital,
  Cambridge University Hospitals NHS Foundation Trust,
  Hills Road, Cambridge, CB2 0QQ
  **Tel:** (01223) 256920
  **Cardiac secretary:** (01223) 217985

- **Consultant paediatric ophthalmologist,**
  Department of ophthalmology,
  Clinic 3, Box 41, Addenbrooke’s Hospital,
  Cambridge University Hospitals NHS Foundation Trust,
  Hills Road, Cambridge, CB2 0QQ
  **Secretary:** (01223) 216700
  **Clinical nurse specialist:** 01223 596414

- **Consultant paediatric dermatologist,**
  Department of dermatology,
  Clinic 7, Box 46, Addenbrooke’s Hospital,
  Cambridge University Hospitals NHS Foundation Trust,
  Hills Road, Cambridge, CB2 0QQ
  **Secretary:** (01223) 216501
  **Clinical nurse specialist:** 01223 217391
Consultant paediatric ear, nose and throat (ENT) surgeon,
Department of ENT,
Clinic 10, Box 48, Addenbrooke’s Hospital,
Cambridge University Hospitals NHS Foundation Trust,
Hills Road, Cambridge, CB2 0QQ
Secretary: (01223) 216486
Clinical nurse specialist: 01223 216162

References/ Sources of evidence

- Great Ormond Street Hospital 2018, Treating haemangiomas with propranolol: information for families

Where to get further information

Birthmark Unit
Tel: 020 7405 9200 ext 1113

Support groups

The Birthmark Support Group offers support and advice to parents of children with all types of birthmark. Telephone their helpline on 0845 045 4700 or visit their website at www.birthmarksupportgroup.org.uk

Changing Faces is another organisation that will be able to offer help and support to anyone living with a condition that affects their appearance. Visit their website at www.changingfaces.org.uk or telephone their helpline on 0845 4500 275.

Privacy & Dignity

Same sex bays and bathrooms are offered in all wards except critical care and theatre recovery areas where the use of high-tech equipment and/or specialist one to one care is required.
We are a smoke-free site: smoking will not be allowed anywhere on the hospital site.
For advice and support in quitting, contact your GP or the free NHS stop smoking helpline on 0800 169 0 169.

Other formats:

If you would like this information in another language or audio, please contact Interpreting services on telephone: 01223 256998, or email: interpreting@addenbrookes.nhs.uk For Large Print information please contact the patient information team: patient.information@addenbrookes.nhs.uk